

Wisconsin Department of Health Services – Division of Public Health

Maternal and Child Health (MCH) / Children and Youth with Special Health Care Needs (CYSHCN) UPDATE

May 2013

The purpose of this **UPDATE** is to share important information on national, state, and local maternal and child health issues, including children and youth with special health care needs, to Title V Maternal and Child Health Block Grant providers. You will also be updated on pertinent resources and state and regional “happenings.” We hope the **UPDATE** will promote statewide sharing and contribute to improved maternal and child health in Wisconsin. Please share this **UPDATE** with others.

DISTRIBUTION

The **UPDATE** will be posted to the [MCH Program website](#) or distributed by request via email. To receive the **UPDATE**, send your name and email address to [Mary Gothard](#).

FORMAT

The **UPDATE** design includes content headings and a table of contents. We hope this enables easier reading and access to the information that pertains to you. The **UPDATE** contains “active links” to content; therefore, it is best read electronically. If you have comments or suggestions for a future issue, contact [Mary Gothard](#) at (608) 266-9823.

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THINGS YOU DON'T WANT TO MISS!

Infant Mortality Initiative

Wisconsin has been invited, along with the other 5 states in Region V (Illinois, Indiana, Michigan, Minnesota, and Ohio) to participate in an Infant Mortality Summit and Collaborative Improvement and Innovation Network (CoIIN), sponsored by the federal Maternal and Child Health (MCH) Bureau and other national MCH partners. During the next 12-18 months, the MCH program and partners, including the Medicaid Program, March of Dimes, City of Milwaukee Health Department, and the University of Wisconsin Lifecourse Initiative for Healthy Families, will develop and implement priority strategies and actions for healthy communities and healthy families. This is a unique opportunity to collaborate with the other states in our region to implement common solutions to reduce disparities in infant mortality, low birth weight, and premature births. For more information, contact [Patrice Onheiber](#) at (608) 266-3894.

BCHP PROGRAM/PARTNER NEWS & EVENTS

Updates: Wisconsin Association for Perinatal Care (WAPC) & the Perinatal Foundation

WAPC has a number of new educational materials intended for consumers, parents, and families. Visit the [WAPC Materials and Publications](#) page to preview and order all of the materials seen below:

- *Becoming a Parent Checklist:* Newly updated in 2013, the preconception checklist is designed for people considering pregnancy to complete prior to their preconceptional consultation. The woman and her partner can review the checklist with their health care provider.
- *Early Pregnancy Information:* Newly updated in both English and Spanish, this brochure was developed for women early in pregnancy who have not had preconceptional care or who experience a delay in getting into prenatal care.
- *Prescription for a Healthy Weight:* Newly created in 2013, the prescription is available in a pad format for easy use by providers. It integrates health messages about nutrition and exercise that are important for women during the childbearing period. Each prescription contains a list of steps a woman can take to reach a healthy weight and therefore improve her overall health.
- *NICU Parents' Wish List:* Newly created in late 2012, this wish list is compiled from responses of parents with infants in NICUs across Wisconsin. This poster displays ways family, friends, and healthcare providers can make parents' time in the NICU less stressful. It is intended to be posted anywhere families, friends, and/or healthcare providers gather.

Public Health Hotlines – Upcoming Webinars

The Maternal Child Health Hotline and Wisconsin First Step are hosting a webinar on May 15, 10 am – 11:30 am. The Webinar is targeted towards local public health department staff throughout Wisconsin and will offer participants the chance to:

- Meet staff from the hotlines
- Learn how the hotlines can help you
- See a demonstration of the On Line Resource Directory
- Learn about the Web Category lists

There are also spots available for non-public health staff who may be interested in attending the Webinar. Participants can register by sending your email address to kjbrandt@gundersenhealth.org or by calling Karen at (608) 775-6331 for more information. The Wisconsin Public Health Hotlines are available 24 hours a day, 7 days a week. Call The Maternal Child Health Hotline at 1.800.722.2295 and/or Wisconsin First Step at 1.800.642.7837. You may access the hotline [website](#) for more information or to search the Online Resource Directory.

CURRENT RESEARCH/NEWS

AMCHP Pulse – Looking Back and Ahead

This [January/February 2013](#) issue of the Association of Maternal and Child Health Programs (AMCHP) *Pulse* focuses on a look back and a look ahead for MCH issues.

Review Explores Risk Factors That May Predispose Infants to Increased Vulnerability to SIDS

"Although it is difficult to attribute an independent risk to a single risk factor, knowledge of clusters of nonmodifiable and modifiable risk factors can be useful to the obstetric care provider in targeting certain patient populations," writes the author of an article published in the *American Journal of Perinatology* online on January 5, 2013. Although a considerable volume of literature has been published, and although guidelines have been revised and updated according to new findings, there is no protocol for preventing sudden infant death syndrome (SIDS) in infants at increased risk. Although there is no way to predict which infant will die of SIDS, many factors that may explain why certain infants are more susceptible have been studied. This article reviews articles published between 1975 and 2011 for risk factors associated with SIDS. The authors found that:

- The following maternal characteristics were consistently associated with increased risk of SIDS: younger, African American, aboriginal, low socioeconomic status, less educated, higher parity, previous premature delivery or intrauterine growth restriction, insufficient prenatal care, smokers, alcohol use, premature rupture of membranes, and postnatal depression.
- The following infant characteristics were consistently associated with increased risk of SIDS: male gender, multiple births, prematurity, low birthweight, and small for gestational age.

"Although interactions between risk factors are strong and thus it is not known that removing exposure to one individual risk factor may decrease the risk of SIDS, some of these factors are amenable to modification," state the authors. "We recommend increased awareness and enhanced educational strategies for populations at higher risk, summarized [above]," the author concludes.

Van Nguyen JM, Abenhaim HA. 2013. Sudden infant death syndrome: Review for the obstetric care provider. *American Journal of Perinatology* [published online on January 5, 2013]. [Abstract](#). NOTE: More information is available from the following MCH Library resource: [Infant Mortality and Pregnancy Loss: Knowledge Path](#).

Taken from January 25, 2013 MCHAlert© National Center for Education in Maternal and Child Health and Georgetown University. Reprinted with permission.

FDA: Resources on Breast Pumps

The Food and Drug Administration (FDA) has updated its resources on breast pumps. The Consumer Update [Breast Pumps: Don't Be Misled - Get the Facts](#) answers a range of questions about the devices, which are used by breastfeeding mothers to "express" or extract milk. FDA oversees the safety and effectiveness of these medical devices, and provides guidance about choosing a breast pump, including how to decide which type of pump will fit in best with a woman's daily routines, and whether pumps sold as "used" are safe. FDA has also updated its [website](#) on breast pumps, providing general information on the devices.

Taken from: Healthy Mothers, Healthy Babies Monday Morning Memo Series. January 28, 2013.

Study: Reasons Behind Breastfeeding Cessation

A study published online on February 18 in the journal *Pediatrics* examines reasons why mothers stop breastfeeding earlier than desired. In [Reasons for Earlier than Desired Cessation of Breastfeeding](#), the study authors analyzed data from monthly surveys of 1,177 mothers aged 18 years and older (conducted from pregnancy until their child was one year of age). Mothers were questioned about whether they breastfed as long as they wanted, and were asked to rate the importance of 32 reasons for stopping breastfeeding. Sixty percent of mothers who stopped breastfeeding did so earlier than

Wisconsin Department of Health Services – Division of Public Health desired. Reasons included concerns regarding difficulties with lactation; infant nutrition and weight; illness or the need to take medicine; and the effort associated with pumping milk. The study authors conclude that continued professional support may be needed to address these challenges and to help mothers meet their desired breastfeeding duration.

Taken from: Healthy Mothers, Healthy Babies Monday Morning Memo Series. February 25, 2013.

Study: Safe Sleep Practices in the NICU

A [report](#) published online on March 4 in the journal *Pediatrics* discusses a project designed to investigate the percentage of infants following safe sleep practices in the neonatal intensive care unit (NICU) before discharge, and to determine if improving compliance with these practices would influence parent behavior at home. (The American Academy of Pediatrics (AAP) calls for NICUs to endorse and model sudden infant death syndrome (SIDS) risk-reduction recommendations prior to discharging infants.) Methods utilized as quality improvement intervention strategies included an algorithm detailing when to start safe sleep practices, a "Back to Sleep" crib card, educational programs for nurses and parents, a crib audit tool and post-discharge telephone reminders. In the NICU, compliance with placing infants to sleep on their backs increased from 39% to 83%, use of a firm sleeping surface increased from 5% to 96%, and the removal of soft objects from the bed improved from 45% to 75%. A post-discharge telephone survey showed that parental compliance with safe sleep practices had improved from 23% to 82%.

Taken from: Healthy Mothers, Healthy Babies Monday Morning Memo Series. March 11, 2013.

Authors Examine Pregnancy Intention & Postpartum Depression Among First-Time Mothers

"Increased risk for postpartum depression was observed in women with prepregnancy depression, and Hispanic or Asian race," write the authors of an article published in the *Journal of Women's Health* online on March 14, 2013. Depressive symptoms during the postpartum period have implications for both maternal and child health. Several international studies have demonstrated an increased risk for postpartum depression after unintended pregnancy, but there is scarce data on the relationship between unintended pregnancy and postpartum depression in U.S. samples. Further research on the relationship between pregnancy intention and postpartum depression in U.S. women could shed light on the clinical and psychosocial needs of women experiencing unintended pregnancies and contribute to policy discussions about family planning. The article presents findings from a study to investigate whether pregnancy intention is associated with prevalence of postpartum depression at one month after birth in first-time mothers, controlling for prepregnancy characteristics. The authors found that:

- Most of the women were white, married, and had a college degree or higher.
- Almost one-third (32.0%) of the pregnancies were unintended. At one month postpartum, 151 (5.1%) of the women met the threshold for postpartum depression.
- Postpartum depression was more prevalent in women with unintended pregnancies compared to women with intended pregnancies (6.7% vs. 4.3%). However, after controlling for the prespecified covariates, unintended pregnancy was no longer significantly associated with postpartum depression (adjusted odds ratio 1.41).
- Prepregnancy depression was the strongest predictor of postpartum depression, with four-fold increased odds. Asian race and Hispanic ethnicity were also independently associated with higher odds of postpartum depression.

"We found that the prevalence of postpartum anxiety/depression was higher among women with unintended pregnancies, but in contrast to previous literature, unintended pregnancy was not independently associated with postpartum depression. Our findings possibly differ from previous reports due to our unique ability to control for prepregnancy anxiety/depression," the authors conclude.

Abbasi S, Chuang CH, Dagher R, et al. 2013. Unintended pregnancy and postpartum depression among first-time mothers. *Journal of Women's Health* [published online on March 14, 2013]. [Abstract](#).

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Report Identifies Promising Practices for Those Serving Pregnant and Parenting Adolescents

[*Promising Strategies and Existing Gaps in Supporting Pregnant and Parenting Teens*](#) presents findings to discuss what works for pregnant and parenting adolescents. The report summarizes discussions among a panel of experts convened by the Office of Adolescent Health. These experts included physicians, university faculty, medical directors, psychologists, researchers, federal staff, and directors of programs and organizations serving pregnant and parenting adolescents. Topics include promising practices in reaching, engaging, and retaining pregnant and parenting adolescents; effective program components when working with pregnant and parenting adolescents; and examples for implementing the core components. Suggestions are provided for advancing education, integrating services and referrals, strengthening participant-provider relationships, articulating program goals and processes, emphasizing family relationships, considering development influences, and developing highly skilled staff and a welcoming program environment. Conclusions, resources, expert panel biographies, and references are included.

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Study: Childhood Celiac Disease & Infant Feeding Practices

A study appearing online February 18th in the journal *Pediatrics* investigates whether infant feeding practices affect the occurrence of childhood celiac disease. Celiac disease is a condition in which eating gluten (a protein found in wheat, barley and rye) causes damage to the small intestine. The disease can cause slow growth and weaken bones in children. In [*Prevalence of Childhood Celiac Disease and Changes in Infant Feeding*](#), the study authors examined and compared the total prevalence of celiac disease in two birth cohorts of 12-year-olds in Sweden and related the findings to each cohort's ascertained infant feeding. Sweden experienced "epidemic" increases in clinical celiac disease in children under age two between 1984 and 1996. Children who were studied were born both before and after this increase. Those who were introduced to dietary gluten in small amounts during ongoing breastfeeding had a significantly lower risk of having celiac disease.

Taken from: Healthy Mothers, Healthy Babies Monday Morning Memo Series. March 4, 2013.

AMCHP Responds to HRSA/CDC Report on Increased Prevalence of Autism Spectrum Disorders in School-Age Children

The prevalence of autism spectrum disorder (ASD) in school-aged children has increased from 1.2% in 2007 to 2% in 2011-2012, or 1 in 50 children, according to a recent report released by the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC). The report was based on parental reporting using the National Survey of Children's Health, a national sample of families across the country. The report, [*Changes in Prevalence of Parent-Reported Autism Spectrum Disorder in School-Aged Children: 2007 to 2011-2012*](#) is available on the [CDC website](#). Last year, the CDC Autism and Developmental Disabilities Monitoring (ADDM) Network estimated that 1 in 88 children had been identified with ASD.

The changes in ASD prevalence were greatest for boys and adolescents aged 14-17, while much of the increase in the prevalence estimates from 2007 to 2011-2012 for school-aged children was the result of diagnoses of children with previously unrecognized ASD.

"The estimates released by CDC and HRSA today help provide more insight into the increasing prevalence with autism spectrum disorder in America," said AMCHP CEO Michael Fraser. "As CDC and

HRSA note, we continue to need more information and understanding of why some children are identified with autism before others, as well as the impact of early and more widespread screening for ASD and other developmental disabilities.

"We do know that the rising numbers of children identified with ASD have led to increased pressure on states to ensure that all children and youth with ASD receive early and timely identification, diagnosis and intervention. State Title V maternal and child health and children and youth with special health care needs programs – through involvement with the HRSA Combating Autism Initiative and CDC *Learn the Signs. Act Early.* campaign – have played key roles in initiating and leading comprehensive efforts to build these systems of care, but we continue to need better understanding of both the disorder and effective screening and interventions to best help families."

For more information about AMCHP work to support systems of care for children and youth with autism spectrum disorder through its State Public Health Autism Resource Center (SPHARC) and work with the CDC *Learn the Signs. Act Early.* campaign, please visit the [SPHARC website](#).

Study: Autism Risk & Number of Vaccines

A new [study](#) published in the *Journal of Pediatrics* shows that there is no association between receiving "too many vaccines too soon" and autism. Despite repeated scientific evidence showing that vaccines do not cause autism, approximately one-third of parents continue to express concerns that they do, with nearly one in ten parents refusing or delaying vaccinations. This latest study shows that the risk of autism is not increased due to the number of vaccines administered, either on a single day or cumulatively over the first two years of life. The study authors analyzed data from 256 children with autism spectrum disorders (ASD) and 752 without ASD from 3 managed care organizations. Each child's cumulative exposure to antigens in vaccines, and the maximum number of antigens each child received in a single day of vaccination, was analyzed. They found that the total number of antigens received by age two years, or the maximum number on a single day, were the same between children with and without ASD.

Taken from: Healthy Mothers, Healthy Babies Monday Morning Memo Series. April 1, 2013.

Journal Supplement Examines Life Course Approach to Understanding Adolescence

The [supplement](#) to the February 2013 issue of the *Journal of Adolescent Health* investigates the neurobiology and development of adolescent health and disease, focusing primarily on what transpires during adolescence and how a young person subsequently responds to the range of environmental demands placed on him or her. The supplement's six articles address the following topics: adolescent neurodevelopment; epigenetics and early life origins of chronic noncommunicable diseases; biological contributions to addictions in adolescents and implications for prevention, treatment, and policy; implications of science for illicit drug use policies for adolescents; implications of neuroscience and genetics on policies and programs to reduce the burden of depression in adolescents; neurobiology of food addiction and adolescent obesity prevention; and reducing adolescent-related violence by building resilient adolescents.

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WISCONSIN DATA TIDBITS & DATA REPORTS

Wisconsin PRAMS – What Moms Tell Us about Gestational Diabetes

The Wisconsin Pregnancy Risk Assessment Monitoring System (PRAMS) survey asks “During *your most recent pregnancy*, were you told by a doctor, nurse, or other health worker that you had gestational diabetes?” The mother is asked to check Yes or No.

Table 1: Percent of Mothers Who Were Told They Had Gestational Diabetes

Race/ethnicity

White, non-Hispanic	7%
Black, non-Hispanic	9%
Hispanic/Latina	12%
Other	14%
Total	9%

Source: 2009-2010 Wisconsin PRAMS, Division of Public Health, Department of Health Services.

Notes: Percentages do not add to 100% because the categories are mutually exclusive.

Nine percent of new mothers reported that they were told that they had gestational diabetes. By race/ethnicity, mothers of minority/racial ethnic groups had the highest percentage of gestational diabetes at 14%, followed by Hispanic/Latina mothers at 12%. African American mothers and white mothers had the lowest percentages at 9% and 7% respectively.

If you would like PRAMS data presented, or for more information, contact [Kate Kvale](#) - Project Director at (608) 267-3727.

MCHB Releases New Resources on Women's and Children's Health

The Health Resources and Services Administration's Maternal and Child Health Bureau has released two reports on the health status and service needs of infants, children, adolescents, children with special health care needs, and women in the United States. Each report reflects an increasingly diverse population, highlights emerging issues and trends, profiles health from a variety of sources, and serves as a reference for policymakers and program managers. The reports include the following:

- [Child Health USA 2012](#) provides both graphical and textual summaries of secondary data on over 50 health-related indicators. Topics include population characteristics; health status of infants, children, and adolescents; health services financing and use; and state, rural, and urban data.
- [Women's Health USA 2012](#) presents a collection of current and historical data on health challenges facing women, their families, and their communities. Topics include population characteristics, health behaviors, health indicators, reproductive and maternal health, special populations, and health-service use.

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Child and Adolescent Health Data

The *Data Resource Center for Child and Adolescent Health* has a great [newsletter](#) and [website](#). Check it out!

CONFERENCES & AWARENESS CAMPAIGNS

Show Your Love Campaign

A new campaign from the Centers for Disease Control and Prevention (CDC) educates consumers, health professionals and policymakers about preconception health. The *Show Your Love* campaign has resources, materials and information about preconception health and health care available on their new [website](#). Preconception health and health care focuses on taking steps now to protect the health of a baby in the future, and is important for all women and men, whether or not they plan to have a baby one day. Healthy Mothers Healthy Babies (HMHB) is a strong partner of the Show Your Love campaign, since preconception care is aligned with our mission and can help all men and women to live healthy lives. Taken from: Healthy Mothers, Healthy Babies Monday Morning Memo Series. February 11, 2013.

Info for Providers on Text4baby

A new [resource](#) for providers from [text4baby](#) provides information on how the program can help educate pregnant and new moms. A new video explains how text4baby works and shares testimonials from providers on how they have successfully enrolled moms in the service. Learn more about the value of text4baby and how it helps reinforce the health and safety messages that you're already sharing with patients. [Watch it now](#) and share it with your colleagues and networks!

Screen-Free Week

[Screen-Free Week](#) is a national celebration during which children, families, schools and communities spend seven days turning OFF entertainment screen media and turning on life! It's a time to unplug and play, read, daydream, create, explore nature, and spend time with family and friends. *Screen Free Week* is scheduled for April 29 – May 5, 2013, but many of the resources are valuable communication tools for parents and community partners all year long. The Centers for Disease Control's Division of Community Health has developed screen-free [infographics](#) and [Lean Time buttons](#).

WEBSITES & TECHNOLOGY-RELATED RESOURCES

AMCHP National Center for Health Reform Implementation

The Association of Maternal and Child Health Programs is hosting a [webpage](#) with information related to the Affordable Care Act (ACA). Check it out!

NEW Wisconsin Nutrition, Physical Activity and Obesity Program (NPAO) Website

The NPAO Program has a new [website](#). The web pages are organized by settings: active communities, healthcare, childcare, schools, food system and worksites. The site also includes [local coalition summaries](#). Check it out!

Stress During & After Pregnancy

A new [guide](#) from the Maternal and Child Health (MCH) Library at Georgetown University directs readers to a selection of current resources that describe some sources of stress that pregnant women and new mothers experience and the impact of maternal distress on the developing fetus and young child. [Maternal Distress in the Perinatal Period and Child Outcomes: Knowledge Path](#) points to policies, programs, and practices that enhance a woman's ability to cope with stress, provide social and emotional support for pregnant women and new mothers, and build protective factors in new families. Health professionals, program administrators, policymakers, and researchers can use the knowledge path to learn more about maternal distress and child outcomes, to integrate what they know into their work in new ways to improve care, for program development, and to locate training resources and information to answer specific questions. A separate brief lists resources for families.

Taken from: Healthy Mothers, Healthy Babies Monday Morning Memo Series. January 22, 2013.

Nourishing Special Needs Network WIC-Birth Defects Statewide Webinars:

- [*Learn the Signs. Act Early. Developmental Milestones Material Available to Wisconsin WIC.*](#) Presented by Carrie Arneson, MS, And Mary Arbuckle, MSW of the Waisman Center. (February 25, 2013).
- [*Breastfeeding Infants with Special Needs*](#) Presented by: Sally Norlin, RD and Sharon Marshall, IBCLC of Meriter Hospital's Neonatal Intensive Care Unit. (April 15, 2013)
- The *Nourishing Special Needs Network* holds bi-monthly conference calls and members will be meeting one hour prior to the May 30, 2013 CYSHCN Collaborators Meeting in Ripon, Wisconsin. Feel free to contact [Amy Ford](#), Waisman Center Project Nutritionist, for more information about the network.

Toolkit Aids Efforts to Support Families Experiencing Intimate Partner Violence and Perinatal Depression

[*A Comprehensive Approach for Community-Based Programs to Address Intimate Partner Violence and Perinatal Depression*](#) highlights strategies and provides resources to help organizations address intimate partner violence and perinatal depression within their own communities. The toolkit, published by the Health Resources and Services Administration's Maternal and Child Health Bureau, comprises eight sections. Topics include making the case, building and sustaining partnerships, raising awareness, developing cultural and linguistic competence, addressing policy, and implementing standards of care guidelines. Pre- and post-program assessment tools and links to national resources are included.

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Educational Videos on ADHD Management & Treatment

The National Association of Pediatric Nurse Practitioners (NAPNAP) has announced the availability of an educational video series for parents and healthcare providers that specifically addresses questions about attention deficit hyperactivity disorder (ADHD). [*Conversations About ADHD Management and Treatment*](#) features two pediatric nurse practitioners who engage in discussions with parents and an adolescent to answer questions about ADHD management in school and treatments. The video series includes ten, one- to two-minute video clips addressing a variety of topics including, but not limited to: an overview of ADHD symptoms and treatments, taking medication and receiving accommodations in school, going away to college, driving and ADHD, and bullying.

Taken from: Healthy Mothers, Healthy Babies Monday Morning Memo Series. February 4, 2013.

CDC Website - Cigarette Smoking Among Persons with Disabilities

In early March, CDC's National Center on Birth Defects and Developmental Disabilities announced a new [web site](#) focusing on smoking and persons with disabilities. Check it out!

CYSHCN PROGRAM

The CYSHCN Program is guided by six National Performance Measures. Content in this section is organized by these six areas: 1) Family Leadership; 2) Medical Home; 3) Screening; 4) Coordinated Services; 5) Health Insurance Coverage; and 6) Transition.

FAMILY LEADERSHIP

- **Parent to Parent of Wisconsin (P2PWI)** believes that *Partnering for Collective Impact* is a result of a layering of partnerships with common agendas and measurements for success. A recent CYSHCN Directors meeting offered attendees the opportunity to assess current partnerships, reflect and review value of partners and identify opportunities to strengthen their collective impact for families and children with special health care needs through maintaining, strengthening or identifying new partnership opportunities.

Recently, P2PWI, the Wisconsin Medical Home Initiative, Southeast Regional Center for CYSHCN and parents have partnered with Southwest Pediatrics to broaden parent leadership and support opportunities. This collaborating partnership helped to strengthen Southwest's Parent Advisory Council (PAC) by identifying parents who were interested in becoming members and by offering a Parent Education evening event for "stressed-out" parents. This idea came from the PAC, which felt this was important for families. Additionally this is possible through collaboration with the New Berlin Public Library, which provides the space free of charge. Check out the Parent Education Evening on April 30, 2013 at the [SW Pediatric's blog](#).

Note: You may learn more about *Collective Impact* at:

<http://www.amchp.org/AboutAMCHP/Newsletters/Pulse/NovDec2012/Pages/Feature5.aspx>
<http://learning.mchb.hrsa.gov/conferencearchives/amchp2013/>

- **Parents in Partnership: Leadership Development**

Parents in Partnership is a group of parents and other caregivers who meet five times during the year to share their family stories, challenges, joys, and triumphs of raising their children; learn about community and statewide resources for children with disabilities; explore issues around health, education, policy making, legislation, inclusion, self-determination, family well-being and IDEA. Sessions are scheduled in Lac du Flambeau, Rhinelander and St Croix Falls. [Online registration](#). For more information contact [Martha DeYoung](#), WSPEI, State Training Coordinator, at (608) 745-5435.

MEDICAL HOME & SCREENING AND IDENTIFICATION

- **Medical Homes @ Work** is the monthly e-newsletter from the [National Center for Medical Home Implementation](#). The March 2013 issue [Spotlight on Child Health Issues: Cultural Effectiveness and the Medical Home](#) focuses on the medical and oral health disparities that exist for children of diverse races and ethnicities. The issue includes promising practices as well as resources for providers, children, youth and families.

- **More Children Receiving Routine Screening of Their Development By Wisconsin Clinicians**

A survey on routine use of developmental and autism-specific screening tools by Wisconsin pediatric primary care clinicians was conducted in late 2012 by the [Wisconsin Statewide Medical Home Initiative](#). One hundred and fifty seven clinicians completed all or part of the survey. Over

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55% of respondents almost always used the general developmental screening tool *Ages and Stages Questionnaire*® (ASQ) and the autism-specific instrument *Modified Checklist for Autism in Toddlers* (M-CHAT) to identify children with possible delays. When screening results warranted further services, over 85% of respondents referred children to the Wisconsin Birth to 3 Program, and over 80% almost always or sometimes provided learning activities for parents to promote their child's development. [Complete survey results](#).

- **Joint Release of Information and Referral to Wisconsin Birth to 3 Program**

This [form](#) was recently approved by Wisconsin Department of Health Services (DHS) and posted to the DHS website for use. The release is both HIPAA and FERPA compliant. Signatures from parents on this single form will allow clinicians and Birth to 3 Program professionals to communicate directly with one another and expedite care for children identified with developmental delays.

- **AAP Guidance on Improving Oral Health in Children with Developmental Disabilities**

Oral Health Care for Children with Developmental Disabilities describes the effect that poor oral health has on children with developmental disabilities and the importance of interprofessional partnerships in advocating for and coordinating care for these children. The clinical report, published in the March 2013 issue of *Pediatrics*, provides basic knowledge of the oral health risk factors affecting children with developmental disabilities as well as the importance of partnerships between pediatric medical and dental homes. Topics include barriers to accessing oral health care, oral health conditions associated with developmental disabilities, oral health education in medical and residency training, identification of children who require referral for dental treatment, and the safe use of procedural sedation and analgesia/anesthesia. The report includes suggestions for pediatricians on incorporating oral health assessments and oral health education into their well-child examinations of children with developmental disabilities.

Norwood KW, Slayton RL, Council on Children with Disabilities and Section on Oral Health. 2013. Oral health for children with developmental disabilities. *Pediatrics* 131(3):614-619. [Abstract](#).

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- **Analysis Looks at Medical Home and School Attendance Among CSHCN**

The results of this study "highlight the importance of family and community care central to the medical home concept and services for children," write the authors of an article published in the February 2013 issue of the *Journal of School Health*. The Medical Home Act of 2007 was enacted to improve effectiveness and efficiency in providing medical assistance under the Medicaid program and child health assistance under the State Children's Health Insurance Program. One of the goals of this act for children with special health care needs (CSHCN) was to increase school attendance. A connection between the health care system and the education system is especially important for CSHCN because these children may spend a great deal of time in both health care and school settings. The time spent in these settings can have an influence on the quality of children's lives and the lives of their families. The article presents results from a study to examine the relationship between medical home and school attendance. The authors found that:

- Among children with medical homes, there were no significance differences in their gender, race and ethnicity, residence, poverty level of household, and education level of household.
- Insured children made up a significantly higher percentage (13%) of children with medical homes compared to their uninsured peers (4%).
- A higher percentage of children whose functional status was reported as some or few functional limitations had medical homes (13%) compared with those with severe functional limitations (2%).
- Children with medical homes were more likely than those without medical homes to be in the highest category of missed school days.

- Children living in households with lower incomes were more likely to have more missed school days than those from households with higher incomes.
- Increases in children's functional limitations were associated with higher odds for more missed school days. Children with severe functional limitations had higher odds of missing 8-14 school days in the past year than those with less-severe limitations.

"One challenge in examining the medical home impact on school attendance is the broad category of children that CSHCN includes. Furthermore, as an operationalized system of care, medical home is not fully developed," state that authors. They suggest that "additional research may be warranted to analyze the association between parental perceptions of their child's health status with number of missed school days."

Willits KA, Troutman-Jordan ML, Nies MA, et al. 2013. Presence of medical home and school attendance: An analysis of the 2005-2006 National Survey of Children with Special Healthcare Needs. *Journal of School Health* 83(2):93-98. [Abstract](#).

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COORDINATED SERVICES

- **The Southeast Regional Center for Children and Youth with Special Health Care Needs** will again sponsor their *Care in the Community Conference* on Thursday, September 26, 2013 at the Radisson Hotel, Milwaukee West in Wauwatosa, Wisconsin from 8:00 a.m. – 3:30 pm with registration beginning at 7:30 a.m. This is the 10th anniversary of the conference and there is a special keynote speaker. Stevie Perkins is an entrepreneur and started a business with his sister called [3ELove](#). He is carrying on the vision of the business in memory of his sister who died due to complications of a surgery related to Spinal Muscular Atrophy. The 3 Es stand for Embrace diversity; Educate your community; Empower each other; Love life. This is a theme that resonates with the work done at the regional center.

In addition to the keynote and young adult panel following it, topics include sibling support, mental health, health literacy and more! There will be a number of youth and parents co-presenting which always adds great value and perspective. This conference provides families and providers the information and tools they need to work together in providing coordinated community-based care. Keep an eye on the [website](#) for more information. Social Worker clock hours will be available.

- **Centers for Medicare & Medicaid Services: Health Care Innovation Awards: Wisconsin**
The Children's Hospital and Health System, Inc., partnering with Children's Hospital of Wisconsin, Aurora Healthcare, and Wheaton Franciscan Healthcare received an award to create an Advanced Wrap Network Model (AWN) of culturally sensitive professional, clinical, and social resources to educate Children's Community Health Plan (CCHP) members on how to effectively navigate the health care system. This intervention, targeted at Medicaid and CHIP beneficiaries in southeastern Wisconsin, will deploy Nurse Navigators and Community Health Navigators to increase use of primary care health homes and reduce emergency room visits and inpatient hospital admissions for beneficiaries. As a result, the program will achieve cost savings, while continuing to improve on HEDIS quality metrics for immunizations, diabetes, asthma, and lead testing.

HEALTH INSURANCE COVERAGE

- **HHS Sets Rules for ObamaCare 'Navigators'**
The Affordable Care Act (ACA) has a provision for Navigators to assist individuals and families who are currently uninsured and/or who may need assistance learning about and understanding the new health insurance options through the health Exchanges created as part of the ACA. On April 3,

Wisconsin Department of Health Services – Division of Public Health
the U.S. Department of Health and Human Services (HHS) released the proposed [Standards for Navigators and Non-Navigator Assistance Personnel](#). This proposed rule states the function, role, and responsibilities for Navigators, the assistants for the federally facilitated and state-partnership Exchanges. Non-Navigators are the assistants in state-based Exchanges. It clarifies conflicts of interest, training and certification, and specifies that states must have at least two types of Navigator entities, and one must be a community- and consumer-focused nonprofit organization. In addition, all Navigators must be able to provide information in plain language that is culturally and linguistically appropriate and accessible to individuals with disabilities and individuals with limited English proficiency. Submit comments about the rule at regulations.gov by 5 pm on May 6, 2013.

Source: Healthwatch, THE HILL'S Healthcare Blog by Sam Baker. April 3, 2013

- **[Reforming Medicaid for Medically Complex Children](#)**

In anticipation of proposals to reform or cut Medicaid funding, this article, by Randall O'Donnell of Children's Mercy Hospital and Clinics, discusses ideas put forth by representatives from children's hospitals to improve care and reduce Medicaid costs for children with complex health conditions. They know that children with complex health needs do not receive coordinated care, even though care coordination leads to better health outcomes and reduced costs. The group attributes fragmented care to the differences in each state's Medicaid program, difficulties in communication between multiple providers, reimbursement systems that do not support integration of care, and many states' failures to authorize or pay for specialty care at hospitals across state lines. To coordinate care and reduce costs for children with complex needs, they propose the creation of Nationally Designated Children's Hospital Networks in Medicaid and the Children's Health Insurance Program (CHIP). These "Centers of Excellence" would establish regional networks to provide [medical homes](#) for children with chronic and complex health needs enrolled in Medicaid and CHIP. Within Medicaid and CHIP, these Centers will 1) create a coordinated system of care; 2) improve the delivery of pediatric care by developing guidelines for care coordination, quality metrics and standards for provider networks; and 3) create a bundled payment or shared savings reimbursement system that supports care coordination and reduces costs. The networks would work with the health providers from whom the children currently receive care to enhance their care. States that choose to participate in the Centers of Excellence and regional network model will pay for services for children with complex health needs, regardless of the state in which the care is provided. By Randall O'Donnell. Pediatrics. April 1, 2013

TRANSITION

- **Ben's Transition Story: An Evolving Journey** - *The National Health Care Transition Center* features [a family story](#) by Barbara Katz, Family Voices of Wisconsin Co-Director and Chair of the Wisconsin Board for People with Developmental Disabilities. The story highlights the journey of Ben Katz, Barbara's 21-year-old son with special health care needs.

"While Ben has increasingly become independent in achieving skills, and will continue to increase his independence, he (like many of us, I imagine) will always need support. This interdependency is not based on a lack of independence; rather, it is reliant on others for mutual interaction, both social and functional. At the core of this interdependence are relationships." Barb Katz

- **Youth in Partnership with Parents for Empowerment (YiPPE): A Leadership Development Opportunity for Youth with Disabilities and Their Parents to Learn About the Transition Process in a Unique Way**

The *YiPPE Program* assists youth ages 15-20 (and their parents) to: learn how to make decisions for themselves throughout the transition process; get involved in their school and community; learn how to be as independent as they can; learn more about self-advocacy and self-determination;

Wisconsin Department of Health Services – Division of Public Health prepare for work and/or college; learn what the future could hold for them; get to know other youth; make friends and have fun. Five weekend sessions are planned in October and November 2013 and January, February and April 2014 at the Tundra Lodge Resort and Conference Center in Green Bay. YiPPE starts at 5:00 p.m. Friday and ends by 3:30 p.m. on Saturday. Youth, along with their parents/guardians, must attend ALL five weekend sessions. For more information contact [Martha DeYoung](#), WSPEI, State Training Coordinator, at (608) 745-5435. [Online registration](#).